



WEST VIRGINIA SECRETARY OF STATE

KRIS WARNER

ADMINISTRATIVE LAW DIVISION

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Office of West Virginia  
Secretary Of State

## NOTICE OF RULE MODIFICATION OF A PROPOSED RULE

AGENCY: Health

RULE TYPE: Legislative

TITLE-SERIES: 64-81

RULE NAME: BIRTH DEFECTS INFORMATION  
SYSTEM

CITE AUTHORITY: W.Va. Code §§16-1-4 and §16-40-7.

The above proposed Legislative rules, following review by the Legislative Rule Making Review Committee, is hereby modified as a result of review and comment by the Legislative Rule Making Review Committee. The attached modifications are filed with the Secretary of State.

**BY CHOOSING 'YES', I ATTEST THAT THE PREVIOUS STATEMENT IS TRUE AND CORRECT.**

Yes

Virginia M Payne -- By my signature, I certify that I am the person authorized to file legislative rules, in accordance with West Virginia Code §29A-3-11 and §39A-3-2.

TITLE 64  
LEGISLATIVE RULE  
DEPARTMENT OF HEALTH  
BUREAU FOR PUBLIC HEALTH

SERIES 81  
BIRTH DEFECTS INFORMATION SYSTEM

**§64-81-1. General.**

1.1. Scope. -- This rule establishes and implements a statewide birth defects information system for the collection and reporting of congenital anomalies and abnormal conditions. This rule should be read in conjunction with W. Va. Code §§16-1-18 and §16-40-1 *et seq.* ~~The W. Va. Code is available in public libraries and on the Legislature's web page, <http://www.legis.state.wv.us/>.~~

1.2. Authority. -- W.Va. Code §§16-1-4 and §16-40-7.

1.3. Filing Date. -- ~~April 29, 2004.~~

1.4. Effective Date. -- ~~April 29, 2004.~~

1.5. Sunset. -- This rule shall terminate and have no further force or effect on August 1, 2032.

**§64-81-2. Application and Enforcement.**

2.1. Application. -- This rule applies to all infants born in West Virginia and to the health care providers caring for children at birth and up to the age of six ~~(6)~~ that are diagnosed with a congenital anomaly or abnormal condition based upon national standards.

2.2. Enforcement. -- This rule is enforced by the commissioner of the Bureau for Public Health.

**§64-81-3. Definitions.**

All terms contained in this rule shall have the same meaning as set forth in W. Va. Code §16-40-1. This section sets forth definitions for terms that are not otherwise defined, but that appear through this rule

~~3.1. Advisory Council. -- The committee appointed pursuant to W. Va. Code §16-40-6 to advise on the establishment and implementation of the birth defects information system.~~

~~3.2.~~ 3.1. Birth Defects Information System -- The data base that contains individual case demographic and diagnostic information maintained by the Office of Maternal, Child and Family Health within the Bureau for Public Health.

~~3.3.~~ 3.2. Congenital Anomaly and Abnormal Condition. -- An abnormality of the body's structure or inherent function present at birth, whether the abnormality is detected at the time of delivery or becomes apparent at a later date.

~~3.4. Freestanding Birthing Center. -- A health care facility in which births routinely occur, that is not licensed under W. Va. Code §16-5B-1 et seq.~~

~~3.5.~~ 3.3. Health Care Providers. -- A physician, or his or her designee, at any medical facility

including, but not limited to private clinics, health departments, and hospitals.

~~3.6. Hospital. A facility licensed as a hospital pursuant to W. Va. Code §16-5B-1 et seq. and Welch Emergency Hospital.~~

~~3.7. Nurse-Midwife. An individual authorized under W. Va. Code §30-15 to practice nurse-midwifery.~~

#### **§64-81-4. Reporting Requirements.**

4.1. Each physician, nurse-midwife, hospital, and freestanding birthing center shall provide information to the birth defects information system on all patients up to the age of six (6) that have been diagnosed with a congenital anomaly or abnormal condition.

~~4.1.a. 4.1.1.~~ The commissioner may not require the reporting of personal identifying information or enter into the system any personal identifying information regarding congenital anomalies or abnormal conditions of a child whose parent or legal guardian objects on the basis of religious beliefs according to W. Va. Code §16-40-2.

4.2. The information shall be provided on forms obtained from the Office of Maternal, Child and Family Health in the Bureau.

4.3. Cases to be included in the information system shall consist of the International Classification of Diseases (ICD) diagnoses. ~~After the information is submitted, the advisory council shall recommend the following types of cases that are reportable to the information system based on national standards. The ICD-10-CM Codes, and the type of cases that are reportable to the information system, as set forth in this section, are non-inclusive, and may be modified to meet national standards~~

| ICD CODE                                                                                                                                          | DIAGNOSIS                                                                  |
|---------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------|
| <del>All Congenital Anomalies (740-759) (Reports would include 4<sup>th</sup> and 5<sup>th</sup> digit attachments, i.e. 740.0 or 743.30) —</del> |                                                                            |
| 740                                                                                                                                               | Anencephalus and similar anomalies                                         |
| 741                                                                                                                                               | Spina Bifida                                                               |
| 742                                                                                                                                               | <del>Other congenital anomalies of nervous system</del>                    |
| 743                                                                                                                                               | <del>Congenital anomalies of eye</del>                                     |
| 744                                                                                                                                               | <del>Congenital anomalies of ear, face and neck</del>                      |
| 745                                                                                                                                               | <del>Bulbus cordis anomalies and anomalies of cardiac septal closure</del> |
| 746                                                                                                                                               | <del>Other congenital anomalies of heart</del>                             |
| 747                                                                                                                                               | <del>Other congenital anomalies of circulatory system</del>                |
| 748                                                                                                                                               | <del>Congenital anomalies of respiratory system</del>                      |
| 749                                                                                                                                               | Cleft palate and cleft lip                                                 |

|        |                                                                                                                                                          |
|--------|----------------------------------------------------------------------------------------------------------------------------------------------------------|
| 750    | <del>Other congenital anomalies of upper alimentary tract</del>                                                                                          |
| 751    | <del>Other congenital anomalies of digestive system</del>                                                                                                |
| 752    | <del>Congenital anomalies of genital organs</del>                                                                                                        |
| 753    | <del>Congenital anomalies of urinary system</del>                                                                                                        |
| 754    | <del>Certain congenital musculoskeletal deformities</del>                                                                                                |
| 755    | <del>Other congenital anomalies of limbs</del>                                                                                                           |
| 756    | <del>Other congenital musculoskeletal anomalies</del>                                                                                                    |
| 757    | <del>Congenital anomalies of the integument</del>                                                                                                        |
| 758    | <del>Chromosomal anomalies</del>                                                                                                                         |
| 759    | <del>Other and unspecified congenital anomalies</del>                                                                                                    |
|        | <del>Specified Conditions in the Perinatal Period (760-763) (including 4<sup>th</sup> and 5<sup>th</sup> digit attachments, i.e., 765.2 or 765.20)</del> |
| 760.71 | <del>Fetal Alcohol Syndrome</del>                                                                                                                        |
| 764    | <del>Slow fetal growth and fetal malnutrition</del>                                                                                                      |
| 765    | <del>Disorders relating to short gestation and low birthweight</del>                                                                                     |
| 766    | <del>Disorders relating to long gestation and high birthweight</del>                                                                                     |

| ICD-10-CM Code                                                                                                                                |                                               |
|-----------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------|
| <u>Chapter Q00-QA0 – Congenital malformations, deformations, chromosomal abnormalities, and genetic disorders; select codes listed below:</u> |                                               |
| <u>Q00.0-Q00.1</u>                                                                                                                            | <u>Anencephaly</u>                            |
| <u>Q01.0-Q01.9</u>                                                                                                                            | <u>Encephalocele</u>                          |
| <u>Q02</u>                                                                                                                                    | <u>Microcephaly</u>                           |
| <u>Q04.2</u>                                                                                                                                  | <u>Holoprosencephaly</u>                      |
| <u>Q05.0-Q05.9, Q07.01, Q07.03</u>                                                                                                            | <u>Spina bifida without anencephaly</u>       |
| <u>Q11.0-Q11.2</u>                                                                                                                            | <u>Anophthalmia/microphthalmia</u>            |
| <u>Q12.0</u>                                                                                                                                  | <u>Congenital cataract</u>                    |
| <u>Q16.0, Q17.2</u>                                                                                                                           | <u>Anotia/microtia</u>                        |
| <u>Q20.0</u>                                                                                                                                  | <u>Common truncus</u>                         |
| <u>Q20.1</u>                                                                                                                                  | <u>Double outlet right ventricle (DORV)</u>   |
| <u>Q20.3</u>                                                                                                                                  | <u>Dextro-transposition of great arteries</u> |
| <u>Q20.4</u>                                                                                                                                  | <u>Single ventricle</u>                       |
| <u>Q20.5</u>                                                                                                                                  | <u>Transposition of great arteries</u>        |
| <u>Q21.0</u>                                                                                                                                  | <u>Ventricular septal defect</u>              |

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| <u>Q21.1</u>                                                                                                | <u>Atrial septal defect</u>                                                                        |
| <u>Q21.2</u>                                                                                                | <u>Atrioventricular septal defect (AVSD)</u>                                                       |
| <u>Q21.3</u>                                                                                                | <u>Tetralogy of Fallot</u>                                                                         |
| <u>Q22.0</u>                                                                                                | <u>Pulmonary valve atresia</u>                                                                     |
| <u>Q22.1</u>                                                                                                | <u>Pulmonary valve atresia and stenosis</u>                                                        |
| <u>Q22.4</u>                                                                                                | <u>Tricuspid value atresia</u>                                                                     |
| <u>Q22.4</u>                                                                                                | <u>Tricuspid value atresia and stenosis</u>                                                        |
| <u>Q22.5</u>                                                                                                | <u>Ebstein's anomaly</u>                                                                           |
| <u>Q23.0</u>                                                                                                | <u>Aortic valve stenosis</u>                                                                       |
| <u>Q23.4</u>                                                                                                | <u>Hypoplastic left heart syndrome</u>                                                             |
| <u>Q25.1</u>                                                                                                | <u>Coarctation of aorta</u>                                                                        |
| <u>Q25.2, Q25.4</u>                                                                                         | <u>Interrupted aortic arch (IAA)</u>                                                               |
| <u>Q26.2</u>                                                                                                | <u>Total anomalous pulmonary venous connection</u>                                                 |
| <u>Q30.0</u>                                                                                                | <u>Choanal atresia</u>                                                                             |
| <u>Q35.1-Q35.9</u>                                                                                          | <u>Cleft palate without cleft lip</u>                                                              |
| <u>Q36.0-Q36.9</u>                                                                                          | <u>Cleft lip without cleft palate</u>                                                              |
| <u>Q37.0-Q37.9</u>                                                                                          | <u>Cleft lip with cleft palate</u>                                                                 |
| <u>Q39.0-Q39.4</u>                                                                                          | <u>Esophageal atresia/tracheosophageal fistula</u>                                                 |
| <u>Q41.0</u>                                                                                                | <u>Small intestinal atresia/stenosis</u>                                                           |
| <u>Q42.0-Q42.9</u>                                                                                          | <u>Rectal and large intestinal atresia/stenosis</u>                                                |
| <u>Q44.2-Q44.3</u>                                                                                          | <u>Biliary atresia</u>                                                                             |
| <u>Q54.0-Q54.3, Q54.5-Q54.9</u>                                                                             | <u>Hypospadias</u>                                                                                 |
| <u>Q60.0-Q60.6</u>                                                                                          | <u>Renal agenesis/hypoplasia</u>                                                                   |
| <u>Q64.10, Q64.19</u>                                                                                       | <u>Bladder exstrophy</u>                                                                           |
| <u>Q64.12</u>                                                                                               | <u>Cloacal exstrophy</u>                                                                           |
| <u>Q64.2</u>                                                                                                | <u>Congenital posterior urethral valves</u>                                                        |
| <u>Q66.0, Q66.89</u>                                                                                        | <u>Clubfoot</u>                                                                                    |
| <u>Q71.0-Q71.9, Q72.0-Q72.9, Q73.0-73.8</u>                                                                 | <u>Limb deficiencies (reduction defects)</u>                                                       |
| <u>Q75.0</u>                                                                                                | <u>Craniosynostosis</u>                                                                            |
| <u>Q79.0-Q79.1</u>                                                                                          | <u>Diaphragmatic hernia</u>                                                                        |
| <u>Q79.2</u>                                                                                                | <u>Omphalocele</u>                                                                                 |
| <u>Q79.3</u>                                                                                                | <u>Gastroschisis</u>                                                                               |
| <u>Q90.0-Q90.9</u>                                                                                          | <u>Trisomy 21 (Down syndrome)</u>                                                                  |
| <u>Q91.0-Q91.3</u>                                                                                          | <u>Trisomy 18 (Edwards syndrome)</u>                                                               |
| <u>Q91.4-Q91.7</u>                                                                                          | <u>Trisomy 13 (Patau syndrome)</u>                                                                 |
| <u>Q96.0-Q96.9</u>                                                                                          | <u>Turner syndrome</u>                                                                             |
| <u>Chapter P00-P96 – Certain conditions originating in the perinatal period; select codes listed below:</u> |                                                                                                    |
| <u>P00-P04</u>                                                                                              | <u>Newborn affected by maternal factors and by complications of pregnancy, labor, and delivery</u> |
| <u>P05-P08</u>                                                                                              | <u>Disorders of newborn related to length of gestation and fetal growth</u>                        |
| <u>P09</u>                                                                                                  | <u>Abnormal findings on neonatal screening</u>                                                     |
| <u>P10-P15</u>                                                                                              | <u>Birth trauma</u>                                                                                |
| <u>P19-P29</u>                                                                                              | <u>Respiratory and cardiovascular disorders specific to the perinatal period</u>                   |
| <u>P35-P39</u>                                                                                              | <u>Infections specific to the perinatal period</u>                                                 |
| <u>Chapter H00-H59 – Diseases of the eye and adnexa; select codes listed below:</u>                         |                                                                                                    |

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| <u>H47.03</u>                                                                         | <u>Optic nerve hypoplasia</u>                                                                      |
| Chapter H60-H95 – Diseases of the ear and mastoid process; select codes listed below: |                                                                                                    |
| <u>H90.0-H90.8</u>                                                                    | <u>Conductive and sensorineural hearing loss</u>                                                   |
| <u>H91.0-H91.9</u>                                                                    | <u>Other and unspecified hearing loss</u>                                                          |
| <u>H90.A</u>                                                                          | <u>Conductive and sensorineural hearing loss with restricted hearing on the contralateral side</u> |

4.4. If a child's parent or legal guardian wants information concerning the child removed from the birth defects information system for religious reasons:

~~4.4.a.~~ 4.4.1. The commissioner shall remove all identifying information from the record, but leave the case in the system for reporting purposes; and

~~4.4.b.~~ 4.4.2. A form for the parent or legal guardian to complete for the removal of the child's identifying information shall be mailed to all birthing facilities and made available upon request at the Bureau for Public Health office and on the Bureau's web page: <http://www.wvdhhr.org/https://bph.wv.gov/>.

### **§64-81-5. Confidentiality.**

5.1. Only those persons employed by the Bureau for Public Health dealing specifically with the birth defects registry shall have access to the database. All others requesting data from the registry shall complete a request form detailing what information is requested and how it shall be used. The person requesting the information then shall be given compiled data with no identifying information attached.

5.2. Anyone who obtains confidential information while implementing W. Va. Code §16-40-1 *et seq.* may disclose it only to reporting sources, persons demonstrating a need that is essential to health related research or care of persons with congenital anomalies and abnormal conditions, or as required or permitted by law.

5.3. Anyone who obtains confidential information while implementing W. Va. Code §16-40-1 *et seq.* shall provide a written statement to the commissioner that he or she fully understands the confidentiality of the information and will maintain it.

5.4. The commissioner may publish reports with statistical data relating to birth defects and other adverse birth outcomes that do not in any manner identify individual patients or individual sources of information ~~are permissible~~, provided that the data is not for such small geographic areas or in categories ~~with few entries that~~, together with other publicly available information, the patients could be identified.

### **§64-81-6. Penalties.**

6.1. Anyone who violates the provisions of ~~W. Va. Code §16-40-1 *et seq.*~~ or this rule is subject to the penalties in W. Va. Code §§16-1-17 and §16-1-18.